DEATH AND DYING
IN
LONG TERM CARE FACILITIES

REPORT

Province of British Columbia
Ministry of Health
Continuing Care Division

AUGUST

Province of
British Columbia

Ministry of
Health

Continuing Care Division
Parliament Buildings
Victoria
British Columbia
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November 3, 1989

To: All Facility Operators

The issues around death and dying in long term care facilities are becoming more and more complex. Many operators have indicated that some guidance or assistance in this area would be helpful and greatly appreciated. In response to this need to preserve the dignity of the client during the dying process, the Continuing Care Division, in conjunction with a Steering Committee, has produced a pair of documents, which we have forwarded for your review and consideration.

1) Death and Dying in Long Term Care Facilities - REPORT; and

2) Death and Dying in Long Term Care Facilities - OPERATIONAL GUIDELINES.

I wish to emphasize that these documents are intended primarily as educational and reference material. They should not be construed as "recommended policies" but, rather, as a vehicle for stimulating thoughtful discussion on this timely topic. If your facility chooses to develop policies in this area, these documents should only be one of many considerations in this process.

We realize we took some "risks" in releasing these documents at this time, but feedback from the industry indicated that there was a pressing need for information in this area and we felt this need superceded spending more time to "fine tune" these documents. We are very interested in your feedback and comments on these documents. After such feedback, we are prepared to make changes and produce a revised version for your consideration.

If you have comments or feedback, or if you have any questions with respect these documents, please contact Mr. Andrew Butler, Regional Director, Metro/Sunshine Coast (387-2527).

Sincerely,

Paul Pallan
Executive Director
Continuing Care Division

c.c. Mr. Andrew Butler
Management Committee

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Foreword

In response to rising concerns from the long term care industry with regards to Living Wills and Do-Not-Resuscitate Orders, the Continuing Care Division has conducted a formal review of this subject. Their significance and role in the absence of natural death legislation, present medicolegal issues which require examination within the context of long term care.

A Steering Committee (Mr. Andrew Butler, Regional Director, Metro/Sunshine Coast and Residential Care; Mr. Gerrit Clements, Senior Solicitor, Legal Services; Dr. John Higgins, Medical Consultant, Hospital Programs Division) was established to facilitate the review, conducted by a consultant for the Continuing Care Division, Dr. Patricia Ngan.

As a result, two documents have been produced and are recommended by Mr. Paul Pallan, Executive Director, Continuing Care Division, for use in long term care industry as reference material and general guidelines:

(1) Death & Dying in Long Term Care Facilities — **REPORT**
(2) Death & Dying in Long Term Care Facilities — **OPERATIONAL GUIDELINES**

The **REPORT** is intended as educational literature, and the **OPERATIONAL GUIDELINES** as a guide for facilities to use in developing policies regarding Death and Dying.

In closing, the author of these documents expresses her gratitude to all Committee members, reviewers and the British Columbia Medical Association — Continuing Advisory Subcommittee (CASC) on Health Care of the Elderly and Long Term Care, for their comments and advice throughout this process.

This **REPORT**: Death and Dying in Long Term Care Facilities consists of two parts.

Part One is a Summary Paper which gives the background to the subject and summarizes key issues regarding Death and Dying in long term care facilities. It is written after consultation on medicolegal issues with Legal Services and Hospital Programs Divisions of the Ministry of Health. This Report takes into consideration these professional perspectives.

Part Two is a Set of Recommended Guidelines based on the above, and established after evaluation of the following documents: Death and Dying in Long Term Care facilities (by Dr. David Wooldridge, CASC*), Joint Statement on Terminal Illness (CNA, CMA, CHA), Living Will documents, Do-Not-Resuscitate Orders, and literature on natural death legislation.

*Chairman, B.C. Medical Association, Continuing Advisory Subcommittee on Health Care of the Elderly and Long Term Care.

Subject Definition

In the management of long term care clients with terminal illness, decisions with respect to treatment (or non-treatment) have to be made during the terminal stage of illness.

Do-Not-Resuscitate Orders, originally developed for application in acute care hospitals, are used by some physicians for clients in long term care facilities. The Order refers only to Cardiopulmonary Resuscitation and although it addresses the situation of cardiac arrest, it does not address the multitude of conditions associated with terminally ill clients. Hence, this subject concerns all long term care clients but particularly those elderly individuals with terminal illness.

Background and Problem Definition

Many long term care facilities have not developed policies or standard procedures for addressing issues regarding Death and Dying in the management of their clients. In practice, decisions with respect to treatment/non-treatment have to be made under a wide variety of medical circumstances and situations, often without the guidance or direction of the client's wishes.

There is no legislation in Canada at the present time for protecting physicians and care staff from criminal or civil actions with regards to treatment/non-treatment of terminally ill persons. The administration of life saving measures in some cases would be inhumane as it may only prolong the dying process. Physicians are obliged to act in the best interest of their patient and must exercise their judgment if the individual is incompetent. Presently, the medical profession is subject to potential liability each time a decision is made under uncertain circumstances.

In some cases, a Do-Not-Resuscitate (DNR) Order may have been previously written by a physician which specifically states that no CPR will be performed if the patient suffers cardiac arrest. However, its validity and ability to address all medical circumstances are questionable. In other instances, the client may have made a Living Will declaration, with or without consultation with the physician. Living Wills, however, are probably non-binding documents as they have no legal status in Canada in the absence of natural death legislation (see Summary Paper — Case Two for further discussion).

Hence in the absence of legislation, long term care facilities should develop policies, based on a separate document, **OPERATIONAL GUIDELINES** from the Continuing Care Division, to set the standard of care for the long term care industry.

So far there has been no civil action against physicians in Canada, but at least two cases have occurred in the United States where a physician was sued for assault for acting against a patient's wishes. It is not acceptable that such important issues remain in a state of uncertainty because this unsettling environment presents potential for litigation. Questions concerning legislation, usefulness of Living Wills, appropriateness of DNR Orders, individual rights versus professional ethics, are all facets of this complex subject.

Proposed Solution

Continuing Care Division has conducted a review of this subject and is presenting this **REPORT** (89.06.06) as a result.

The Report consists of two parts: Part One is a Summary Paper which presents the subject, examines medicolegal issues regarding Death and Dying through case scenarios, and discusses relevant legal principles. Part Two is a set of Recommended Guidelines, based on Part One.

In support of this, a second document, **OPERATIONAL GUIDELINES** (89.06.06) is written.

This will be the working document from which Long Term Care Facilities will develop their own Policies and Procedures. The **OPERATIONAL GUIDELINES** provide a structural framework, whereby individual characteristics such as client mix, administrative/staff profile and the facility's philosophy can be incorporated.

Summary Paper

This Paper examines issues regarding Death and Dying for clients in long term care facilities (as opposed to patients in acute care hospitals).

These clients, mostly elderly, include the chronically ill and those with terminal illness. Terminal illness can be defined as one where natural death will result regardless of life-saving measures. These are usually degenerative diseases. Life saving or 'heroic' measures in these cases may include activities such as: use of life support systems, organ transplants, vascular surgery, Cardiopulmonary Resuscitation, administration of drugs (antibiotics), blood transfusions, intravenous and naso-gastric feeding. Issues and related problems are addressed in two sections (following the Definitions):

Section A: those issues which arise in situations leading to the writing of a DNR Order by the physician, and

Section B: those issues pertaining to the use of a DNR Order in long term care facilities.

DEFINITIONS

Living Will (LW)

The Living Will is a declaration (not an Order) made by an individual, while competent, which indicates whether to withhold or administer treatment (and the type of treatment) during the terminal stage of illness, if he/she becomes incompetent or is unable to express his/her wishes at that time. The onus is on the individual to make such a declaration.

The Living Will is not an Order (unlike a Do-Not-Resuscitate Order, written by a physician and legally binding on care staff), but is an important indication of the client's wishes regarding treatment. The physician should take this into consideration in determining whether an Order is appropriate for the client.

Do-Not-Resuscitate (DNR) Order

This Order is written by a physician after consultation with the patient and/or his family. It is binding on care staff and remains effective (until retraction by a physician), unless the patient's condition has changed significantly in a manner not previously foreseeable. The Order indicates that CPR should not be attempted if the individual experiences cardiac arrest.

'Degree of Intervention' (DI) Order

The proposed 'DI' Order would also be written by a physician and legally binding on care staff. However, it is more comprehensive than the DNR Order as it allows greater consideration of treatment options, often required in the management of Long Term Care clients (Section B).

'Degree of Intervention' Conference

A meeting to be conducted by the facility for the client to discuss 'Degree of Intervention' to be taken during final stage of illness or in the event of a sudden collapse. The conference will include, where appropriate, the client (if competent), family members, physician and relevant care staff of the facility.

SECTION A

The following scenarios provide a framework for examining existing problems and issues with respect to the writing of a DNR Order by a physician.

Case One: Competent Individual

If the individual is competent, then the physician need only discuss treatment decisions with this individual and his/her wishes should be respected. This principle of autonomy is based on the fact that a competent person has a right to refuse treatment, even if the decision seems foolish to others. This holds true if the person is of sound mind and is well informed of the medical condition and its ramifications. Physician and care staff should, however, be aware of situations where the individual may be under duress. Thus, a physician cannot impose treatment against the wishes of the competent adult. Furthermore, disagreement of any other person (including family members) is irrelevant to the decision of the competent client.

Case Two: Incompetent Individual

If the individual is incompetent then the physician must base the decision of whether to write a DNR Order, by using any source of indication as to the patient's previous wishes (made while competent), regarding treatment. Such indications may have been expressed in a Living Will or communicated to family members. Whether a Living Will has been written or not, the physician should consult with family members (if available) in making treatment decisions for the incompetent patient.

In Canada presently, there is no 'natural death' legislation. Although, as a result, Living Wills probably have no legal status, their value as an indication of a person's wishes should be taken seriously. To illustrate: in the Ontario Case of **Malette** vs. **Shulman**, the High Court awarded damages to a Jehovah's Witness, against the doctor who performed blood transfusion despite the discovery of a Jehovah's Witness' card (expressing denial of consent to blood administration) found on the patient. The Court's decision is accepted as a possible precedent for cases concerning Living Wills should an analogous situation occur in British Columbia.

Although the autonomy of a competent adult is clearly recognized in common law, the Law Reform Commission of Canada does not support natural death legislation at the federal level. Their main argument is that if legislation is enacted, it may undermine the 'natural' rights of a competent adult to refuse treatment. This may lead to situations where a physician will administer (or refuse to discontinue) treatment if the patient has not signed a Living Will. The Law Reform Commission, however, has recommended changes to the Criminal Code for the protection of physicians from criminal charges of murder or manslaughter in administering or withholding treatment to terminally ill patients. These recommendations would also sanction the administration of palliative care in the comfort of the dying, even if such care may result in reduced life expectancy.

In addition, there are other problems concerning the Living Will document itself. Firstly, the document cannot replace (be fully representative of) the individual making the declaration, as it may not address all situations where guidance is required.

Secondly, the imprecise language with respect to medical conditions and treatment measures may lead to conflicting interpretations among medical staff and family members.

Thirdly, the physician must consider the validity of a Living Will, especially if he/she was not consulted at the time of its declaration. Significant changes in medical condition or prognosis may have occurred in the interim.

Case Three: **Incompetent Individual, No Living Will**

If no Living Will exists for the incompetent client, family members would have to be consulted by the physician and medical staff, and a consensus would have to be reached with respect to the DNR Order. If a consensus cannot be reached, one possible solution would be the designation of a proxy. Although there is merit in this, it is not a viable solution in practice as there is no legislation in this regard at the present time.

Provincial legislation is required to give legal recognition to decisions made by a proxy. Nova Scotia is the only Province so far which has enacted the *Medical Consent Act* in this respect. Appropriate legislation would:

1. recognize the validity and authority of a designated proxy,

2. give legal status to decisions made by a proxy, and

3. establish the process for proxy selection in cases where the individual is found to be incompetent (and no proxy has been appointed by the individual while competent).

A valid (legally recognized) proxy might, in fact, be a better representative for the incompetent client than a Living Will, as the proxy would be able to assess situations as they occur when decisions are required.

Theoretically, a committee of the person can be appointed by the Court to make medical decisions, but the expense and time involved render this procedure impractical.

Case Four: **Incompetent Individual, No Living Will, No Family Members**

The importance and value of a designated proxy is particularly evident in cases where family members do not exist or cannot be reached. Decisions made by such a proxy can only be binding under appropriate legislation. A DNR Order (if appropriate) may be written by a physician in such cases, but this leads to an entire legal problem in itself, in the absence of consent.

The first four cases present scenarios where prior consideration of treatment decisions was possible, resulting in the writing (if appropriate) of a DNR Order.

Case Five: **Physician Making Treatment Decisions for Client**

In the event that the client (competent) or his/her family (if incompetent) is not prepared to make decisions regarding treatment options, and has designated the physician to assume this responsibility, this should be documented for the protection of the physician and facility from potential liability.

Case Six: **No Prior Consideration**

There may be cases where prior consideration of the matter was not possible, resulting in the physician/nurse or care staff having to make a decision in a crisis situation. It is crucial that policies be developed (in the absence of legislation) for facility staff regarding appropriate actions to be taken, in setting the standard of care for the facility.

Finally, an effective DNR Order means that no resuscitative efforts should be made if the client suffers a cardiac arrest. Conversely, there should be a policy regarding the documentation of a doctor's decision **not** to write a DNR Order. One should distinguish this from the case where no consideration of the matter was possible. For instance, a sudden heart attack of an elderly individual in the absence of an Order does not necessarily warrant implementation of CPR.

SECTION B

This section examines the application of the DNR Order in long term care facilities, particularly for clients who are elderly and terminally ill.

The DNR Order as mentioned, pertains to only one type of treatment, namely CPR for cardiac arrest. However, there are other circumstances associated with terminal illness which require life saving measures that correspond to different treatment interventions.

The main problem of the DNR Order is its lack of comprehensiveness. The Order is too restrictive for long term care applications as it only refers to one type of treatment. For clients in long term care facilities it is appropriate to consider the 'Degree of Intervention' Order.

The definition proposed by Levenson et al has been adopted by B.C. Medical Association CASC to reflect the following Degrees:

Degree One:	Supportive care, such as nursing care, relief of pain, fluids, control of fever, etc.
Degree Two:	Therapeutic measures within the limits of the institution such as supportive care and medication.
Degree Three:	Transfer to acute care hospital if necessary.
Degree Four:	Maximum therapeutic effort as in Degree Three, including intensive care and CPR.

An Order which uses this concept allows a continuum of care options, as opposed to a single discrete intervention (as in a DNR Order). Thus the 'Degree of Intervention' Order offers greater flexibility in treatment options to an individual. It should be emphasized however, that in the application of a 'DI' Order, the aforementioned problems discussed in Section A, still remain.

In particular:

1. The Living Will is (probably) still a non-binding document, although an important one for the physician to consider, in the process of deciding whether an Order is appropriate for the individual.

2. Proxy designation will not be effective without proper legislation. The situation of an incompetent client with no Living Will or family member is of particular concern.

3. In addition, the validity of the proposed 'DI' Order must be reviewed over time by the physician with the client if competent, and/or family members if incompetent.

CONCLUSION

It should be kept in mind, that the underlying objective is to provide the best possible care for clients in long term care facilities, in compliance with their wishes or that of their families. Decisions in treatment and care plan made by the physician and care staff should take into consideration the wishes of the client if competent, or any declaration such as a Living Will or the opinions of the family if incompetent.

Respect for the (competent) client's autonomy does not imply however, neglect of professional judgement. A physician is not obliged to continue treatment (against his/her own judgement) under futile circumstances even though it is insisted upon by the competent adult. (In practice, another physician is sought, who would agree with the patient's wishes.)

Recommended Guidelines

These Guidelines, in support of the Summary Paper of Part One, indicate the position and intent of the Continuing Care Division with respect to Death and Dying in long term care facilities.

The Guidelines are presented chronologically according to events leading to the writing of a 'Degree of Intervention' Order.

Policies should address the following:

1. 'Degree of Intervention' Order: definition
   : the concept of 'Degree of Intervention'
   : replacement of the DNR Order
   : function in the overall care plan of a long term care client.

2. Competence:

   a policy regarding the determination (by the physician) of a client's competence to make treatment decisions.

3. In the case of a competent client:

   the principle of autonomy will be respected. The client is the only relevant person to be considered in deciding on intervention options.

4. In the case of an incompetent client:

   the use of any indication as to the client's wishes regarding treatment (made while competent) such as a Living Will (if one available) or consultation with family members (if available).

5. Sudden collapse:

   In the case where no prior consideration of the appropriateness of a 'DI' Order was possible, the facility should have a policy indicating what degree of intervention (if any) will be undertaken by staff members.

6. 'Degree of Intervention' (DI) conference:

   The importance and purpose of the 'DI' conference to discuss treatment interventions and the DI Order. A time frame for action should be stated.

7. Communication:

   There should be designation of a facility staff member responsible for communicating to family members, decisions made with regards to the 'DI' Order.

8. Documentation:

   Results of conferences and meetings held, including Living Will declaration, changes, and any Order which may have been written will be documented.

   A decision by the physician NOT to write a 'DI' Order will be recorded as having been discussed, and a future date set to review this decision.

9. Scheduled Reviews:

   A review process to re-examine the appropriateness of a Living Will declaration or 'Degree of Intervention' Order in relation to the client's current wishes, medical condition and prognosis should be established.

It should be noted that the designation of a proxy either by a competent client or by others (if incompetent) is not a viable option at present.

Since there is no legislation recognizing the validity of a proxy, any decisions made by a proxy are not binding. In the event that they are in conflict with those of family members, physician or an existing Living Will, this leads to greater difficulty in reaching a consensus regarding treatment for the incompetent client.

Procedures for achieving specific tasks in compliance with the above policies should include:

1. Client orientation : regarding 'Degree of Intervention' Order and 'Degree of Intervention' conference

   : designation of a facility staff member for the coordination of this orientation.

2. Competence assessment: facility should ensure that the physician involved in the 'DI' conference is satisfied with the client's competence to make treatment decisions. The physician's assessment must be clearly documented.

3. Conference review : the criteria for determining an appropriate review schedule for Living Will declaration or 'Degree of Intervention' Order should be stated.

4. Communication : mechanism for communicating to family members, decisions or changes made regarding 'DI' Order.

5. Sudden collapse : procedure (plan of action) for the 'Degree of Intervention' (if any) to be undertaken by facility staff.

A formalized set of guidelines is recommended for policy development, and are found in the separate document: Death and Dying in Long Term Care Facilities — **OPERATIONAL GUIDELINES.**

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